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STATE OF NEW HAMPSHIRE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
DIVISION OF PUBLIC HEALTH SERVICES
BUREAU OF FAMILY HEALTH AND NUTRITION
MATERNAL AND CHILD HEALTH SECTION

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Newborn Screening Advisory Committee Meeting Minutes

October 24, 2023

11:00am- 1:00pm

Physical Location:

SOPE Hazen Conference Rooms 311/312
NH Department of Health and Human Services
29 Hazen Drive, Concord, NH 03301

Virtual Option:

Microsoft Teams meeting
Meeting ID: 276 417 416 543
Passcode: Jrb5y

Virtual Attendees: Marissa Avolio, Amy Foster Bosco, Vernon Clough, Roger Eaton, Melissa Josefiak, Courtney Keane, Amy Kritzer, Paula Minnehan, Sue Moore, Matthew Ryzewski, Inderneel Sahai, Shari Wilmot. **In Person Attendees:** Amanda Merrill, Carolyn Nyamasege, Rhonda Siegel, Kristen Smith.

▪ WELCOME AND INTRODUCTIONS

▪ PROGRAM UPDATES:

- Courtney Keane, MS, Administrator -Newborn Screening Programs
 - Courtney informed the committee that as of November 17, 2023 Kristen Smith will become FTE with the NBS Program. This will leave an open PTE position in the program.
- Amanda Merrill, BSN, RN NBS Program Coordinator
 - 2021 Legislative Report presented to legislation on June 23, 2023. Can be viewed on our website.
 - NBS Program working on finalizing 2022 Annual Legislative report, goal to present this around February 2024.
 - Staffing of the program allowed for FTE to attend 2023 APHL NBS Symposium in CA and two PTE to attend the 2023 APHL CQI Conference in GA.
 - Filter paper changes made with SFY 2024 filter paper order, those changes include: addition of a submitter box in the hospital of transfer field, removal of “if either of these answers is yes, another blood sample will be needed” in the transfusion section, added “another sample required by 48 hours of age” next to the question, “Is less than 24 hours of age” and provided a box for the recorders initials and the collectors initials.
- Rhonda Siegel, MEd, Administrator Maternal Child Health, co-chair
 - HB 308- Passed legislative committees will need to have 1/3 of the committee members in person to hold a vote.

- Still looking for co-chair for the committee as well as parent or persons affected with a disorder that we screen for in NH. Susan M. and Paula M. have ideas for open committee positions. Will meet with Rhonda after meeting to discuss.
 - Meetings will continue to be held hybrid biannually.
- **UMASS LAB UPDATE:**
 - Roger Eaton, Director, UMass New England Newborn Screening Program
 - Roger updated the committee on status of most recently added RUSP disorders, GAMT and MPS-II. Reagents used for screening of Lysosomal Storage Disorders (LSD) will not be available next year. The new reagent kit used will require the lab to modify the existing testing for current LSD's (Pompe and MPS1). This new kit will make it easier for the lab to add testing for MPS-II. Roger is anticipating a target date of testing for MPS-II to begin around August 2024. As for GAMT, Roger explained that this can be added to the current method for testing Acylcarnitine disorders and Amino Acid disorders, however the lab will need to revalidate their internal standards, as updated standards now exist and are more ideal than previously available. Roger anticipates screening for GAMT to be available around January 2025.
 - In Feb 2023, Krabbe Disease was nominated for inclusion on the national RUSP, however the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) did not recommend to the Secretary the addition of Krabbe disease to the RUSP as it was a tie vote. This has been put up for expedited review. Next ACHDNC meeting in November.
- **NBS HRSA GRANT:**
 - Shari Wilmot, RN, MPH, NBS Program Specialist
 - Shari presented on HRSA Propel Grant awarded to the NBS Program. Period of performance: July 1, 2023- June 30, 2028. Funding amount of \$340,000 per year for 5 years. Reviewed Focus Area #1 which include activities related to improving the collection of specimens, testing of specimens, and reporting our results including improving timeliness of these activities and implementation screening for newly added RUSP conditions. Focus Area #2 that includes activities related to improving short term follow up through long term follow up and helping families understand and navigate the process from confirmation of a diagnosis to treatment, and through follow up across the lifespan. Discussed NBS Program specific activities and objectives.
- **GAMT- A FAMILY STORY:**
 - Kim Tuminello, Mom of child affected with GAMT, Director of Advocacy at The Association for Creatine Deficiencies (ACD)
 - Kim presented to the committee on her son and daughter's journey through detection, diagnosis and treatment of GAMT. Reviewed cost-efficient treatment options. Identified states that currently screen for GAMT. Informed the committee that those states who screen for GAMT show a low false positive rate and shared

that those who do screen found that the cost of screening is low. Provided resources and supports available for families with GAMT.

▪ **ADJOURNMENT**

- Rhonda Siegel, MEd, Administrator Maternal Child Health, co-chair
 - Will follow up with committee members who fit criteria to fill co-chair position as no volunteers from the committee.
 - Will follow up with members on the committee for ideal candidates for empty positions. Asked that the committee forward the contacts of any parents or persons affected with a disorder that we currently screen for to fill empty parent advocate seat.